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Vote Yes on HB 477

Testimony of Cort Freeman, Butte, Montana

Ben Mattlin is a Harvard graduate, contributing editor at *Institutional Investor* and *Financial Advisor* magazines, National Public Radio commentator, and author. Writing in The New York Times on Oct. 31, 2012, he counts himself as a pro-choice liberal who ought to support physician-assisted suicide, but as a lifelong disabled person, he cannot. With plenty of room for abuse, Mattlin says, physician-assisted suicide is a bad idea. Coercion often is subtle and often misunderstood. Thus, I support HB 477.

Here's Mattlin: "My problem, ultimately, is this: I've lived so close to death for so long that I know how thin and porous the border between coercion and free choice is, how easy it is for someone to inadvertently influence you to feel devalued and hopeless — to pressure you ever so slightly but decidedly into being 'reasonable' to unburdening others, to 'letting go.'"

He goes on to say that, while the push for physician-assisted suicide comes from many who have seen a loved one suffer, supporters of it can't truly conceive of the many "subtle forces — invariably well-meaning, kindhearted, even gentle, yet as persuasive as a tsunami — that emerge when your physical autonomy is hopelessly compromised."

Mattlin was born with spinal muscular atrophy. He has never walked, stood, or had much use of his hands. Half of babies with this condition die within two years. Today, Mattlin, at 53, is a husband, father, journalist and author.

When a hospital blunder compromised his health further, doctors questioned whether his life was worth saving. Mattlin writes, "They didn't know about my family, my career, my aspirations." His wife rescued him.

From this he learned how easy it is to be perceived as someone whose quality of life is untenable and how this becomes one of many invisible forces of coercion. Others include, "that certain look of exhaustion in a loved one's eyes, or the way nurses or friends sigh in your presence while you are zoned out in a hospital bed."

Mattlin writes that this can cast a dangerous cloud of depression upon even the most cheery of optimists. He says, "Advocates of Death with Dignity laws who say that patients themselves should decide whether to live or die are fantasizing. We are inexorably affected by our immediate environment. The deck is stacked."

Montana can do better with improved care. HB 477 can move Montana in this caring direction by making physician-assisted suicide unlawful. Please vote yes on HB 477.

YES on HB 477

HB 477 before the Senate Judiciary Committee today makes a connection regarding two other bills that are before the **senate committee on education** -- teacher training to prevent student suicides and bullying. HB 477 favors hope and life for all Montana citizens by making physician-assisted suicide not an option.

Dr. Eric Arzubi, a psychiatrist from the Billings Clinic, testified for mandatory teacher instruction in suicide prevention. During that House hearing, he answered a question on bullying and suicide, bringing them together. Arzubi said when people are tormented beyond their breaking point, death becomes preferable to life. And if there have been recent suicides, then killing oneself becomes a more viable option. But if hope is the nurturing principle then life becomes the norm.

Generally, "Bullying" means any harassment, intimidation, or threatening, insulting, or demeaning gesture or physical contact directed against a person that is repeated or persistent and that creates a hostile environment by interfering with or denying access to an opportunity or benefit. Bullying includes coercion.

People who are disabled or in nursing homes or extended care – especially those with limited support or ability to defend themselves – can be subject to bullying or subtle coercion: intolerant families abandon them, mean staff deride them, rude nurses demean them, busy doctors over look them.

This is not me talking. In Montana, Adult Protective Services are provided by the Senior and Long Term Care Division of the Montana Department of Public Health and Human Services (DPHHS), to reduce or remove the risk of physical or mental harm that has occurred or is occurring to a person, as a result of abuse, neglect or exploitation. I believe there are five state agencies carrying out this directive.

Ben Mattlin is a Harvard graduate, journalist and author. Writing in the New York Times, he counts himself as a pro-choice liberal who ought to support physician-assisted suicide, but as a lifelong disabled person, he cannot. With plenty of room for abuse, Mattlin says, physician assisted suicide is a bad idea.

He says many who have seen a loved one suffer can't truly conceive of the many subtle forces in favor of suicide: How easy it is for someone to inadvertently influence you to feel devalued and hopeless — to pressure you into being 'reasonable' to unburdening others, to 'letting go.'

He says, "Advocates of Death with Dignity laws who say that patients themselves should decide whether to live or die are fantasizing. We are inexorably affected by our immediate environment. The deck is stacked."

My testimony includes a one-page version of Mattlin's comments. Please read it.

HB 477 favors hope for those contemplating suicide, that they are loved and cared for. This is the right message to prevent suicides – for all Montanans. Please vote yes on HB 477.

Dear Friends.

By way of a very brief intro, I am a 69 year old woman, a lifelong Democrat, I support marriage equality, a woman's right to choose (in the days preceding Roe v. Wade I stood on street corners in Ann Arbor, MI getting petition signatures), and have engaged in civil disobedience/resistance over the past 45 years as part of number of civil rights groups, including women, Native Americans, disability rights and peace.

I want you to understand my progressive politics because the one issue on which I differ from many of my liberal/progressive colleagues and friends is the issue of physician assisted suicide.

You have already received some of my thoughts on this issue, and today I am writing to ask you to read a blog entry from my friend Amy Robertson, a civil rights attorney who is currently partnering with the Montana ACLU on a case. Like me, Amy is married to a wheelchair user who is also her law partner. Together they and their firm, the Civil Rights Education and Enforcement Center, have made national news with discrimination wins against huge corporations.

Please take her words to heart as you thoughtfully consider your vote on HB 477 on Monday.

Thank you, Marsha Katz Missoula, MT

THOUGHT SNAX

http://thoughtsnax.com Food for thought . . . in small tasty bites

Dignify THIS!

I'm done. I'm done being polite.* I'm done shutting up about good liberals who seem to get every sort of civil rights and civil liberties except the equality of rights, respect, and dignity of our brothers and sisters with disabilities. I'm done with disability rights as a "when we get around to it" right. I'm done with people who are willing to use respectful terminology except — *big sigh* — avoiding using the word "retard" is just one step too far toward thought control. And I'm done with "civil rights" law firms in inaccessible offices and "civil rights" lawyers who don't hire interpreters. I'm done.

What pushed me over the edge was this voicemail, from a fellow attorney who would, I believe, describe himself as favoring civil rights. I suppose it's my one last shred of not-yet-quite-doneness that leads me to keep him anonymous.

But who he thinks he is and who his words and actions show him to be should not be anonymous. It needs to be out there for good liberals — chock full of self-righteousness and non-disabled privilege — to observe and perhaps see themselves. And become real civil rights lawyers by according people with disabilities the same rights and respect you accord other groups you work so hard for.

First let's play the "protected class switcheroo" game. Imagine I got this voicemail:

Hey Amy, [Name Redacted] here. Trying to get in touch with you and/or Tim. I'm working with a group that is sponsoring legislation to increase penalties for disrespecting police officers. They got bogged down because of some African-American, ah, community concerns – said it would be used as a sword instead of a shield. Um, I think it's miscommunication. I think the African-American community should be absolutely in favor of it and I wanted to hook up with folks, the right folks, in the African-American community and I thought you would know the behind the scenes politics of who best to contact.

Pretty gross, eh? No good liberal would talk that way, at least not in public in 2015. This is, in fact, the voicemail I received. Verbatim.

Hey Amy, [Name Redacted] here. Trying to get in touch with you and/or Tim. Um, I've done work in the past through when I was at the ACLU with the Hemlock Society; they're now the Compassion and Choices organization and they sponsored some legislation about right to choose or to refuse treatment. They got bogged down because of some disability, ah, community concerns – said it would be used as a sword instead of a shield. Um, I think it's miscommunication. I think the disability community should be absolutely in favor of it and I wanted to hook up the Compassionate Choices people with folks, the right folks, in the disability community and I thought you would know the behind the scenes politics of who best to contact.

And here is my response:

[Name Redacted] -

500

Thanks for your voicemail. I think I can say with a fair degree of confidence that there was no miscommunication on the disability rights side. The position of CCDC, Not Dead Yet Colorado, and a long list of prominent disability rights groups opposing physician assisted suicide is well thought out and thoroughly researched. I can't possibly improve on the information on NDYCO's website, so I'll provide a link: http://www.notdeadyetcolorado.org/.

To be clear, Colorado's bill was not about refusing treatment: anyone can do that at any time without the proposed legislation. It is also not about choices: we can all choose to buy a gun and shoot ourselves; to drive in front of a train; to stop eating and drinking; etc. Instead, the discussion revolves around getting a doctor to assist you in killing yourself to avoid — tracking the title of the bill — an *undignified* death. What is characterized as "lack of dignity," however, are conditions that many people with disabilities live and thrive with every day: the need for a vent; a feeding tube; colostomy; urostomy; assistance with activities of daily living. Statistics from Oregon, for example, a state that has legalized assisted suicide, demonstrate that people do not chose assisted suicide to relieve intractable pain — the purpose for which it has been sold to the public — but rather to address perceived loss of autonomy, inability to engage in activities of daily living, and loss of dignity.

These perceptions and the urge to kill oneself over them result directly from a society that does not value people with disabilities — and such perceptions are (circularly) reinforced by bills like these and the rhetoric that surround them. Assisted suicide is urged in an environment in which people with disabilities do not have universal access to attendant care in their homes and communities, to assistive technology and mobility devices, to accessible vehicles or modifications, or to home modifications — hell, to accessible homes to start with. These are all things that people need to continue to live — with dignity — in the community. In the absence of this sort of support, many disabilities fit the bill's definition of "terminal," making it the worst sort of health care rationing: cheaper dead than disabled.

A bill proposing that it was "undignified" to live as an African-American, an LGBT* person, or — to take an historical example — as a Jew, thereby justifying easy access to death would be rejected with horror. Yet good liberals appear completely at home with providing a cheap and easy path to death for people with disabilities.

Furthermore, the concerns of people with disabilities reflect a great deal of thought and considered analysis; it is patronizing to suggest that they result from miscommunications. I can't imagine any other group active in the civil rights dialog that would be the subject of a voicemail like this. When LGBT* groups oppose civil rights rollbacks, are they perhaps just victims of a miscommunication, which can be corrected by identifying the "right" groups? How about African-Americans calling for law enforcement reform? Shall we identify the "right" groups to support our men and women in blue?

The debate over physician assisted suicide has been plagued by this sort of condescension, as liberal and radical disability rights groups are accused of being pawns of religious conservatives, as if incapable of independent thought. This infantilizing of our movement underscores our fears that disability is so stigmatized that ostensible civil rights champions would rather be dead than disabled.

Ultimately, if the ACLU is devoted to nondiscriminatory civil liberties, it should support a universal right to assisted suicide. Anyone, anytime, can request a lethal dose, not just those in circumstances defined in terms of a protected classification. This I would support, though I believe other members of the disability rights community are more compassionate than I am.

I would be happy to put you in touch with any of the groups on this list to help with any miscommunications:

- Access & Ability Colorado
- ADAPT
- ADAPT Colorado
- Assn of Programs for Rural Independent Living
- Autistic Self Advocacy Network
- · The Center for Rights of Parents with Disabilities
- Colorado Cross-Disability Coalition
- Disability Rights Center
- Disability Rights Education and Defense Fund
- Justice For All
- National Council on Disability
- National Council on Independent Living
- National Spinal Cord Injury Association
- Not Dead Yet USA
- Not Dead Yet Colorado
- Patients' Rights Action Fund
- TASH
- The World Association of Persons with Disabilities
- The World Institute on Disability

Amy

^{*} Yes, I know, there is clear and convincing evidence that I was done with politeness, as a general matter, a long time ago.